

in charter

ETHICAL, LEGAL, SOCIAL ISSUES AND HUGO

ETHICS REVISITED

As this Council deliberates over HUGO's ethical, legal, social issues (ELSI) involvement, there are clearly many different types of proposals for action. The decisions that you are asked to make differ in that some pertain to matters of format and process while others are clearly identified with approving or rejecting content or personnel (see Loder's discussion paper).

Because ELSI cover a wide spectrum of possibilities, it was a deliberate decision to move slowly in finalizing the formation and charge of HUGO's ethics committee. HUGO's limited funds mean that it was never a realistic option to have a stand-alone program. For this reason, it was expected that HUGO would work closely with the funding agencies and we have been waiting for the different national ethics programs to evolve. Having now witnessed the formation of the various agendas and needs, this would seem to be the ideal time for the Council to revisit its intentions toward HUGO's participation. I would suggest that prior to making decisions about specific initiatives, the Council might reconsider the following:

- Is it useful for HUGO to be involved with these issues?
- Does HUGO need to have its own Committee and for what purpose? What tasks?
- Does HUGO see its role as neutral service facilitator or advocate policymaker or both?
- Does HUGO want to internationalize ELSI in the same way that it attempts to internationalize the chromosome work, informatics, and intellectual property?
- Given HUGO's nonfunding role, how can HUGO realistically contribute or even be a factor?

AMERICAS PERSPECTIVE

From the very first Howard Hughes Medical Institute draft proposal to obtain Americas funding, HUGO was advised by HHMI officials to make ELSI a major part of the request. In discussions with funding agencies, it also became very clear that ELSI were both politically and socially mandated. In the final version of the HHMI proposal and in direct response to European sensitivities, ELSI were mentioned but placed within the context of educational initiatives.

The Americas participants are extremely empathetic with the European concerns specific to ELSI. However, since many European organizations and governing bodies have already created ELSI working groups, the precedent for need in this area has already been established and accepted within Europe. Coupled with the significant commitment to ELSI by U.S. funding agencies, it would seem that for HUGO to maintain its claim as the global genome representative, it must become involved.

To provide a forum for discussion of the ethical, ~~social~~ legal and societal ~~and~~ implications of the genome project ~~and~~ the information it will generate was one of 3 stated purposes of HUGO at its founding. After playing the major role in ~~the~~ coordinating the international effort and collecting the

for HUGO not to be involved in
seem unthinkable that important aspects of the
data, it would be coordinating also the effective, beneficial, and humane
use of the information.

* There are many ways to participate in this type of program. HUGO could sponsor meetings by lending its name, could initiate meetings of specific interest, etc. In the case of one pending grant submitted to a joint review panel at NIH and DOE, a database for ELSI publications specific to ^{the} genome has been proposed. HUGO Americas has already been approached about helping to provide the introductions to the relevant global community. Should this proposal be funded, HUGO Americas could be providing a service that facilitates internationalizing this resource.

This type of ~~facilitator role~~ is exactly what NIH and DOE had in mind when requesting HUGO's (through HUGO Americas) involvement in staffing a proposed international ethics steering committee. The U.S. agencies approached HUGO Americas because there is a real possibility that such a committee will be initiated for the purpose of coordinating ELSI activities. If other world-wide funding agencies come to an agreement about this idea, the U.S. agencies would be willing to provide their share of the financial support. As a part of that support, the agencies asked HUGO Americas to consider ~~becoming the staff~~ ^{providing} ~~for~~ ^{support for} that committee.

The NIH/DOE Ethics Advisory Group felt that HUGO would be the appropriate vehicle for providing the staffing services while offering HUGO a defined role in ELSI. Through this supporting function, HUGO could also begin to educate the committee by using its direct ties to the international scientific community. NIH and DOE approached HUGO because they were looking for an agency to help ... "encourage public debate and provide information and to advise on the scientific, ethical, societal, legal and commercial implications of human genome projects..." (quoted from the *Articles of Incorporation of HUGO*).

The NIH/DOE Program Advisory Committee stood ready to publicly name HUGO as the designated entity of choice to provide this coordinating function on behalf of the U.S. genome project. It was very clearly stated that the details of the proposal were obviously forthcoming. It was also clearly stated that any final or binding sanctioning of this ethics committee plan was dependent upon the official approval of the participating agencies and governing bodies. There was very little time between the origination of the idea and the meeting of the U.S. Advisory Committee on 25 June. The HUGO Executive group meeting in Moscow on 18 June was asked to allow this public designation of HUGO to proceed. The Executive was not comfortable in doing so and no action was taken on 25 June by NIH and DOE.

^{The} It would be fair to say that U.S. agencies are struggling to assist HUGO with finding its niche, given the constraint that HUGO is not a funding organization. ^{therefore} U.S. agencies would still like to see HUGO take its place as a viable partner to their own programs. This hopeful attitude toward HUGO is based on nothing more than wanting HUGO (or some other similar type of organization) to succeed in its stated goals.

While HUGO has attempted to maintain its image as one international organization, the reality is that regional laws and cultures do intervene. The constraints upon funding as well as upon each office's operational priorities and style are heavily dictated by regional needs and interests. This is not contradictory to HUGO's mission. The failure to recognize regional differences, however, could eventually impede progress and complicate each office's ability to work within its own national environment.

For HUGO to serve the international scientific community well, it must be able to balance regional interests and needs against possibly conflicting international ones. That is, after all, HUGO's mission...to coordinate differences in ideas, values, systems; to coordinate the science that is funded by other organizations. Through the process of acknowledging, articulating, and exploring global differences, HUGO may be able to find the common road toward collaborations.

Hughes Grant and Ethics

On 12 August, in a brief meeting with the Hughes Grants and Special Programs officials, a discussion about the past and future HUGO Americas agenda took place. This discussion revolved around the review of the funding from HHMI. The only specific program that they wanted to discuss was ELSI.

The officials were very disappointed that HUGO Americas was not visibly active in ELSI. It was stated that HHMI Trustees supported the HUGO grant, in part because of the interest in this area. There was a strong expectation that HUGO Americas, working closely with government funded programs and the funding agencies, would have developed a role for itself in this arena.

The European concerns over ELSI were explained. Officials were told that a discussion on ELSI was scheduled for a 23 August Council meeting. While there was sympathy for the European situation, it was clear, however, that HHMI has given money for HUGO Americas activities. ELSI may be one area where HUGO must acknowledge regional needs. Based upon the outcome of the 23 August meeting, HUGO Americas has been asked to provide a report on its revised programmatic agenda for review by HHMI officials in September.